A Research Proposal:

Caregiver Role Strain and Burden in Guardian Caregivers of Pediatric Oncology Hematopoietic Stem Cell Transplantation Patients

Honors Thesis (HONORS 499)

by

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Abstract

Guardian caregivers of pediatric oncology patients who have been treated with hematopoietic stem cell transplantation (HSCT) are at risk for caregiver role strain and burden. This paper presents a research proposal for nurses interested in exploring caregiver role strain and burden in this population. A convenience sample of ten guardian sets of pediatric oncology patients who have been treated with HSCT should be utilized. Methodology will consist of interviews of caregivers for background information (Form 1); using open-ended questions and therapeutic conversation (Table 1); and using the Marwit-Meuser Caregiver Grief Inventory Childhood Cancer (MM-CGI Childhood Cancer). Data will help nurses identify areas of caregivers' lives that are affected during their child's treatment as well as the degree of grief they are experiencing. With this information, nurses can then develop interventions to help reduce the specific areas of burden and decrease a caregiver's degree of role strain.

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CHAPTER I

Introduction

Cancer is a group of diseases of multiple causations characterized by defective cell growth and differentiation (Lewis, Heitkemper, Dirksen, O'Brien, & Bucher, 2007). The human body has a predetermined number of undifferentiated stem cells that ultimately differentiate into the various functioning cells that make up tissues within the body. The mature cells of each tissue then function as appropriate for the tissue type until they eventually degenerate and die as part of the natural life cycle of the cell.

An intracellular mechanism triggers cell growth, where, under normal conditions, cell growth equals cell degeneration maintaining equilibrium (Lewis et al., 2007). Cellular degeneration and cell death or a physiologic need activate cellular proliferation and growth. As an example, an increase in thrombocyte proliferation may be triggered by trauma or bleeding. Contact inhibition, or cells' tendency to stop growing when they come in contact with another cell, is another mechanism that controls cell proliferation.

Normal function of the intracellular mechanism controlling proliferation is lost when a mutation occurs in the stem cell. One of three events can occur when a stem cell mutates: cellular death from damage or apoptosis, recognition of the mutation that signals repair, or survival with resultant passing along of the mutation to its daughter cells (Lewis et al., 2007). In the third scenario, these daughter cells are at risk of becoming malignant, though cancer may develop from normal tissue cells as well.

Cellular differentiation also may be affected in cancer. In normal healthy cells, cellular differentiation involves a specific progressive process of cellular maturation into the specific functioning cells of a given tissue. Under normal conditions, cells are not

able to regress to an undifferentiated state. During the maturation process, mutation may occur in protooncogenes, genes that regulate cell processes, or tumor suppressor genes, genes that regulate cell growth, causing disruption in the differentiation and proliferation cycles of the cell (Lewis et al., 2007). For example, when mutation occurs in the protooncogene, as may occur in exposure to carcinogens, cells gain the ability to revert back to their fetal, less differentiated, characteristics and appearance.

Additionally, proliferation of malignant cells tends to follow the same rate of proliferation as the cell type from which it originated, but the growth is continuous and breaks the normal rules of equilibrium and contact inhibition. Malignant cells grow without regard to cell degeneration and physiologic need, and they can grow on top of one another as well as on top of and between other healthy cells. Irregular growth and unpredictable distribution throughout the body creates major challenges when trying to treat cancer (Lewis et al., 2007).

According to Lewis et al. (2007), the goal of cancer treatment is cure, control, or palliation. The goal is determined by tumor cell type, location, size, and systemic metastasis. The most common cancer treatments are surgery, chemotherapy, radiation therapy, biologic and targeted therapy, and hematopoietic stem cell transplantation (HSCT). Surgical therapy may be used to reduce the risk of cancer development in patients with predisposing conditions or as a cure for a localized tumor. It also may be used as an adjuvant to other therapies; as a cytoreductive measure; or for creation of colostomies, insertion of gastric tubes, and placement of venous access devices (Lewis et al., 2007). With any surgery comes the risk of complications such as infection, bleeding, and respiratory impairments. Surgery also requires recovery time, the length and rigor of

which depends on the procedure. Surgical procedures may also require a change in lifestyle, such as the patient who requires a permanent colostomy following a bowel resection from colon cancer.

Chemotherapy involves the use of chemical agents as a form of systemic treatment for cancer. The goal of this treatment is to reduce or eliminate the number of malignant cells in the body. Cell cycle phase nonspecific chemotherapeutic drugs affect all cells – malignant and normal – during all phases of the cell cycle. Cell cycle phase-specific chemotherapeutic drugs affect all cells during a specific phase in the cell cycle, such as during replication (Lewis et al., 2007). These drugs are often used in tandem to maximize the effects of the agents. Because systemic chemotherapy fails to distinguish between normal and malignant cells, several side effects result from damaging healthy cells. These effects are classified as acute, delayed, or chronic. According to Lewis et al. (2007), acute toxicity results in anaphylactic and hypersensitivity reactions, cardiac dysrhythmias, and extravasation. Delayed effects include but are not limited to alopecia, nausea and vomiting, myelosuppression, anorexia, mucositis, skin reactions, diarrhea, constipation, fatigue, reproductive changes, central nervous system changes, and peripheral neuropathy. Chronic effects include long-term damage to such organs as the lungs, heart, liver, and kidneys. Patients who have received chemotherapy also may be at risk of developing secondary cancers.

Radiation therapy involves the distribution and emission of energy into tissues to break chemical bonds in DNA. Lethal damage to cellular DNA results in the prevention of replication and impairs the protein synthesis essential for survival of the cell (Lewis et al., 2007). Sublethal damage may not result in immediate cell death, but may ultimately

lead to death through toxic accumulating effects. Because radiation therapy focuses energy to a localized field, it is not appropriate for systemic treatment, though it may be used as an adjuvant to other therapies that are systemic. Side effects of radiation therapy may include but are not limited to burns to the skin and tissue irradiated, damage to organs irradiated (i.e. radiation to the pelvis may lead to infertility in females), fatigue, mucositis, nausea and vomiting, alopecia in radiation to the scalp, myelosuppression, anorexia, and risk of developing secondary cancers.

Biologic therapy modifies the host-tumor response by having direct antitumor effects, changing the immune system response to the tumor, or acting upon the tumor cells' ability to proliferate or differentiate. Targeted therapy involves targeting specific cellular pathways and receptors in tumor growth and may include tyrosine kinase inhibitors, monoclonal antibodies, vascular endothelial growth factor receptor inhibitors, and proteasome inhibitors (Lewis et al., 2007). The administration of each of these therapies may lead to the endogenous release of other internal biologic agents, resulting in inflammatory and immune responses. Side effects of biologic and targeted therapies consist of nausea, anorexia, fatigue, headache, chills, myalgia, weakness, photosensitivity, diarrhea, and urticaria. Some agents may cause capillary leak syndrome, which can cause tachycardia, hypotension, and pulmonary edema.

In patients with certain cancers that do not respond to conventional chemotherapy dosing, radiation therapy, or who have relapsed, hematopoietic stem cell transplantation may be an option. Hematopoietic stem cell transplantation (HSCT) is a treatment used for both malignant and nonmalignant conditions and allows for the safe use of high-dose chemotherapy with or without radiation therapy. The term hematopoietic stem cell

transplantation is the general term replacing reference to bone marrow transplantation, where stem cells are obtained from the bone marrow, and peripheral stem cells transplantation, where stem cells are obtained from the peripheral blood. The goal of HSCT is cure (Lewis et al., 2007).

HSCT involves eradication of cancer cells and the engraftment of stem cells. The patient is treated with doses of chemotherapy that would be dangerous without stem cell recovery due to pancytopenia and other effects with or without radiation therapy. Once the tumor cells are eliminated and remaining bone marrow is destroyed, the patient is infused with stem cells to produce new blood cells. In allogeneic transplantation, donor cells are tested and determined a match for human leukocyte antigen (HLA) tissue typing to ensure compatibility of the transplanted cells. Donors are often family members, though donors may also be unrelated and found through national registries (National Marrow Donor Program, 2010). Indications for allogeneic transplantation in oncologic conditions children may include acute myeloid leukemia, chronic myeloid leukemia, second remission or high-risk acute lymphoblastic leukemia, and relapsed or high-risk non-Hodgkin's lymphoma (Schmidt-Pokorny, 2009).

Some conditions warrant treatment through autologous transplantation, where the patient receives his or her own stem cells after receiving myeloablative chemotherapy. Once the cells are obtained from the patient, they are treated to purge any malignant cells before transplantation back to the patient. Indications for autologous transplantation in the pediatric oncology population may include relapsed Hodgkin's lymphoma, advanced neuroblastoma, and relapsed or advanced solid tumors (Schmidt-Pokorny, 2009).

Regardless of whether the transplant is allogeneic or autologous, HSCT is associated with significant morbidity and mortality (Hockenberry & Wilson, 2009). For example, with allogeneic transplantation, though there is also an increased possibility that the donor's cells may attack any malignant cells in the recipient, there is also an increased risk of graft-versus-host (GVH) disease, a potentially serious condition where the donor cells attack the recipient. Symptoms of GVH may begin seven to thirty days post-transplant and include maculopapular rash beginning in the palms and soles of the feet and possibly leading to generalized erythema and desquamation, liver disease beginning as mild jaundice with the potential to become as serious as hepatic coma, and gastrointestinal distress ranging from diarrhea and abdominal cramping to bleeding and malabsorption. Infection is of paramount concern because the patient's immune system is still weak and the treatment includes further immunosuppression. In patients who do not experience GVH, infection is still a major concern post-transplant until the cells begin to proliferate and differentiate into a mature immune system, which usually takes two to four weeks (Lewis et al., 2007).

Given the significance of the malignant conditions, therapies, and treatment side effects, caregiver role strain and burden is common in guardian caregivers of patients with cancer. Guardian caregivers of pediatric oncology patients either who have undergone HSCT are at a particularly high risk of developing caregiver role strain and subjective and objective burden because their children are in the hospital for at least four weeks following transplant and require meticulous infection control measures and careful observation for GVH. In addition to the acute worries of their child's condition, the guardian caregivers must balance the needs of their other children, personal health,

finances, work, and their personal relationships (Blanchard, Albrecht, & Ruckdeschel, 1997). They also must consider the long-term effects of transplantation and chemotherapy and/or radiation therapy on their children, which may include secondary malignancies, organ damage, infertility, and neurological changes (Hockenberry & Wilson, 2009; Lewis et al., 2007).

Background and Significance

According to the American Cancer Society (2009), there were an estimated 559,8888 cancer-related deaths in the United States in 2009, making it the second-leading cause of death behind heart disease in the United States. Though the risk of cancer increases with age, cancer affects all sexes, ethnicities, and age groups. Cancers of the lung and bronchus are by far most fatal types of cancer in both men and women, causing 30% of cancer-related deaths in men and 26% of cancer-related deaths in women (American Cancer Society, 2009). Although cancer remains a leading cause of death in America, cancer death rates have decreased 16% from 1991 to 2006. This is largely due to an increased focus on prevention and early detection.

Cancer is the second-leading cause of death in children ages one to fourteen years behind accidents in the United States (Jemal, Siegel, Ward, Hao, Xu, & Thun, 2009). Sixteen in 100,000 children and teens were diagnosed with cancer in 2006, and three in 100,000 died as a result of disease or treatment (U.S. Cancer Statistics Working Group, 2010). The most common childhood cancers were leukemia and brain and other nervous system cancers, with 4.3 out of every 100,000 people under twenty years diagnosed with leukemia in 2006 and three of every 100,000 people under twenty years diagnosed with a nervous system cancer in 2006 (U.S. Cancer Statistics Working Group, 2010). Also in

2006, 0.7 of every 100,000 people under 20 died of leukemia whereas 0.6 of every 100,000 people under 20 died of a central nervous system cancer (U.S. Cancer Statistics Working Group, 2010). Despite the fact that cancer is a leading cause of death among children, deaths associated with childhood cancer are declining due to an improvement in treatments in the past twenty-five years (Centers for Disease Control and Prevention, 2007). HSCT has provided a treatment for high-risk and relapsed cancers that do not respond to chemotherapy, and according to Schmidt-Pokorny (2009), twenty to twenty-five percent of HSCT in North America are performed on children. The five-year survival rate for all childhood cancer sites was 80% for those diagnosed in 1996-2004 compared with 58% in those diagnosed in 1975-1977 (Jemal et al., 2009).

However, although treatments are improving and cancer deaths are decreasing among children, it remains a leading cause of mortality in children and a significant source of stress for their guardian caregivers (Al-Gamal, Long, & Livesley, 2009; Ow, 2003). This study will serve to identify specific stressors that caregivers of pediatric oncology patients who have undergone HSCT experience and explore the role strain placed on these guardian caregivers.

Statement of Problem

HSCT is associated with significant morbidity and mortality (Hockenberry & Wilson, 2009). Due to the nature of the treatment and acuity of the diseases that it treats, guardian caregivers of pediatric oncology patients treated with HSCT are at risk for developing caregiver role strain and burden (Herdman (Ed.), 2009).

Statement of Purpose

The purpose of this study is to explore caregiver role strain and burden in guardian caregivers of pediatric oncology patients who have undergone or are waiting to undergo hematopoietic stem cell transplantation.

Research Questions

This study will provide answers to the following research questions:

- To what degree do guardian caregivers feel as though the caregiver role has resulted in personal sacrifice burden? Heartfelt sadness and longing? Worry and isolation?
- What is the total grief level of guardian caregivers?
- What specific stressors has HSCT placed on the guardian caregivers? Family?
- How has HSCT affected personal relationships within the family? Roles within the family?

Theoretical Framework

Lazarus and Folkman (1984) suggest that coping is an ongoing dynamic process that involves cognitive and behavioral forces to manage external and/or internal demands placed on an individual. The guardian caregiver of a pediatric oncology patient treated with HSCT is at risk for significant stress and role strain related to external and internal stressors (Herdman (Ed.), 2009). This theory will be used as the framework to explore caregivers' stressors throughout the study.

Definition of Terms: Conceptual Definitions

Caregiver Role Strain: According to *NANDA International nursing diagnoses: Definitions and classification 2009-2011* (2009), caregiver role strain is in Domain 7: Role Relationships, Class 1: Caregiving Roles of nursing diagnoses and is defined as

"difficulty in performing family caregiver role" (Herdman (Ed.), 2009, p. 201). The defining characteristics include difficulty and apprehension about caregiving activities; physical, emotional, and socioeconomic effects on caregiver health; and effects on the caregiver-care receiver relationship. Related factors include the health status of the care receiver, the health status of the caregiver, the relationship between the caregiver and the care receiver, activities involved in caregiving, family processes, resources, and socioeconomic considerations (Herdman (Ed.), 2009).

Caregiver subjective burden: The subjective burden of care is the psychological distress experienced by caregivers (Fadden, Bebbington, & Kuipers, 1987; Ow, 2003). This may include grief, a sense of loss, anxiety, or depression.

Caregiver objective burden: The objective burden of care refers to the external stressors that caregivers experience, such as disruptions in family interaction, housekeeping, finances, resources and work-related activities (Ow, 2003).

Definition of Terms: Operational Definitions

Marwit-Meuser Caregiver Grief Inventory Childhood Cancer (MM-CGI Childhood Cancer): The MM-CGI Childhood Cancer is a survey used to measure personal sacrifice burden, heartfelt sadness and longing, and worry and felt isolation in parent caregivers of pediatric oncology patients. The original MM-CGI was developed to measure these experiences in caregivers of Alzheimer's patients but was modified by Al-Gamal et al. (2009) to measure anticipatory grieving in Jordanian parents of pediatric oncology patients (Al-Gamal et al., 2009; Marwit & Meuser, 2002; Meuser & Marwit, 2001). The modified version of the MM-CGI will be used as a quantitative piece to the qualitative questionnaire in Table 1.

Limitations

Limitations may include the sample size as well as a sample collection from a midwestern hospital only. Lack of cultural diversity and diverse health and treatment histories may also be limitations. In addition, this study only seeks to interview guardian caregivers, though other family members may be able to provide useful insight as well.

Assumptions

This study will be grounded in the following assumptions:

1. Guardian caregivers of pediatric oncology patients who have undergone HSCT experience caregiver role strain and burden.
2. Guardian caregivers of pediatric oncology patients who have undergone HSCT experience grief.
3. HSCT treatment affects personal relationships within the family.

Summary

Guardian caregivers of pediatric oncology patients that have been treated or will be treated with HSCT are at risk for caregiver role strain and burden. The severity of the disease and the treatment contribute to several emotional, practical, social, and financial stressors placed on the caregivers. This study will focus on exploring the subjective and objective burden and role strain experienced by these caregivers.

CHAPTER II

Introduction

Guardians are the natural caregivers of their children. However, when a child is diagnosed with cancer and faces serious treatments such as HSCT, the guardian caregiver is at risk for developing caregiver role strain and burden. The purpose of this study is to explore the specific stressors and role strain that guardian caregivers of pediatric oncology patients who have undergone HSCT experience.

Organization of Literature

The following review of literature consists of selected studies related to caregiver role strain and burden. The first section will provide a brief description of the framework that will guide the theory of coping in this study. The second section will provide a basis for general caregiver role strain and burden. The third section will focus on specific studies exploring caregiver role strain in caregivers of oncology patients.

Theoretical Framework

Coping is the "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 141). This theory suggests that coping is a process and requires effort on the part of the individual and focuses on "what the person actually thinks or does" (Lazarus & Folkman, 1984, p. 142). Stress is defined as a "relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (Lazarus & Folkman, 1984, p. 19). In the stress process, there is primary appraisal, where the individual evaluates the stressor for well being, and secondary appraisal, where

the individual evaluates interventions to manage the stressor. Lazarus and Folkman (1984) also identified problem-focused coping and emotion-focused coping. In problem-focused coping, the individual implements strategies "directed at managing or altering the problem causing the distress" (p. 150), whereas emotion-focused coping is "directed at regulating emotional response to the problem" (p. 150). This framework of stress and coping can be related to processes of stress and coping in legal guardian caregivers of pediatric oncology patients treated with HSCT.

General Caregiver Role Strain and Burden

Caregiver role strain and burden are terms used to describe the feeling of stress and overwhelmed that caregivers experience (Fadden et al., 1987; Herdman (Ed.), 2009; Honea, Brintnall, Given, Sherwood, Colao, Somers, & Northouse, 2008; Ow, 2003). Sanders, Ott, Kelber, and Noonan (2008) focused on the grief component that caregivers of Alzheimer's disease and related dementias (ADRD) experience. The population consisted of forty-four spouses and adult children caregivers, and a short-form of the MM-CGI (MM-CGI-SF) was administered and revealed seven emerging themes in those that experienced high levels of grief. The themes included yearning for the past, regret and guilt, isolation, restricted freedom, life stressors, systemic issues, and coping strategies. Coping strategies included pets, social supports, and spiritual faith. Further quantitative studies revealed that the seven themes were unique to the caregivers experiencing high levels of grief versus those experiencing low to moderate levels of grief. Sanders et al. (2008) suggest that supportive interventions focus on reducing feelings of isolation, guilt, loss, and regret while increasing feelings of freedom and familiarity with coping strategies.

Caregiver Role Strain and Burden in Oncology Population

Gaugler, Linder, Given, Kataria, Tucker, & Regine (2008) examined indicators of emotional stress linked to care that negatively impacted caregivers' perceptions of family members, finances, and schedules and resources to prevent caregivers from these stressors. The sample included 186 caregivers recruited from radiation medicine clinics at the University of Maryland Greenebaum Cancer Center (UMGCC) in Baltimore, Maryland. Inclusion criteria required that participants consider themselves the primary caregivers of the patient. Participants were then divided into two samples. One sample was recruited over a year and participated in a cross-sectional study of cancer caregiver stress (n = 103), while the other sample participated in a year-long longitudinal study of cancer caregiving stress and the stress process (n = 83; summer 2004-2006). Demographic data was collected. A five-item subscale of Caregiver Reaction Assessment of Given et al. (2007) was used to measure lack of family support (α = .83), whereas four-item subscales of the same Caregiver Reaction Assessment were used to measure financial support (α = .68) and care provision on the caregiver's schedule (α = .67) (Given, Given, Stommel, Collins, King, & Franklin, 2007). Subscale responses ranged from 1 = "strongly agree" to 5 = "strongly disagree." The researchers concluded that caregivers who worked had less financial strain, and those who were older or of greater income had less scheduling strains and more family support.

Primary objective stressors were measured through examining the extent of help required to perform activities of daily living (ADLs) such as bathing, dressing, and eating (α = .80) and instrumental activities of daily living (IADLs) such as shopping, housework, and finances (α = .84). Responses ranged from 0 = "no help," to 1 = "some

help," and 2 = "a lot of help." Results concluded that those who cared for patients with great ADL dependency were more likely to experience a lack of family support, whereas the opposite was true for those who cared for patients with great IADL dependency.

Gaugler et al. (2008) also explored involuntary aspects of the caregiving role (α = .77), role overload (α = .82), and feelings of emotional and physical separation from the patient (α = .84) using a set of three-item subscales measuring primary subjective stressors (Perlin, Mullan, Semple, & Skaff, 1990). Primary subjective stressors were predictors of secondary stress. Greater role overload resulted in scheduling stress, financial burden, lack of family support, and loss of intimacy with the receiver of care. An additional eight-item measure assessed cohesion within the caregiver's social network (α = .91) and found that those who indicated optimism for care were less likely to indicate a lack of familial support. Socioemotional support appeared to help alleviate secondary stress, financial stress, scheduling stress, and family tension (Gaugler et al., 2008).

Ow (2003) investigated subjective and objective burden of care in Asian parents of pediatric oncology patients. A questionnaire was developed and conducted face-to-face to thirty-two participants from twenty-eight families within three months of the child's diagnosis (T1) and again three to six months after diagnosis (T2). Due to death, lack of interest in the study, and relapse, T2 consisted of twenty-two participants from twenty families. Questions in T1 included "What was your first reaction to the diagnosis of your child?" "Do you feel there is an explanation for your child's illness?" "If yes, what do you think it is? Please describe." "Are both you and your spouse working? If yes, how did you manage with work, looking after the home ad the ill child at the same

time?" "Are you satisfied with the current arrangements?" "If yes, why? If not, what were the problems encountered?" "If there are other children, who looks after them when the ill child is in the hospital?" (Ow, 2003). The investigator found that distress among the parents was reported as high and included fear (n = 5), worry (n = 7), sadness (n = 7), shock, disbelief, and lack of acceptance (n = 13), sense of hopelessness (n = 3), and guilt (n = 6) – all indicators of subjective burden. Objective burden was a secondary priority to these caregivers at T1 (Ow, 2003).

Questions in T2 included "Since the first interview, are there any changes to your feelings to the diagnosis of the illness?" "What do you now feel is the explanation for your child's illness?" "Are there any changes to what you first thought?" "If yes, how did these changes come about?" "Do you tend to seek more information about your child's illness? If yes, what kind of information?" "Was it easy to communicate with doctors, nurses, and social workers about what you need to know? If yes, what helped? If not, why?" "Besides professionals in the hospital, did you talk to other people to help you understand your child's illness? If yes, what questions did you ask them?" (Ow, 2003). At T2, personal emotional need, an indicator of subjective burden remained a top priority for caregivers followed by a need for informational resources. This need evolved because the diagnosis still was perceived as threatening to the family, particularly in patients who were not responding well to treatment. Also, contact with medical professionals and social workers decreased with time, reflecting the parents' increased need for information. Objective burden of care decreased over time following the initial hospitalization period for the child.

Summary

Several factors influence the degree to which a guardian caregiver experiences strain and burden. Quantitative and qualitative approaches have been used to study these influences as well as to identify specific stressors. However, further research is needed to explore the specific impact of HSCT on guardian caregivers of pediatric oncology patients.

CHAPTER III

Introduction

A three-part study measuring demographic information, qualitative data, and quantitative data will be conducted to examine caregiver role strain and burden in guardian caregivers of pediatric oncology patients treated with HSCT.

Research Question

- To what degree do guardian caregivers feel as though the caregiver role has resulted in personal sacrifice burden? Heartfelt sadness and longing? Worry and isolation?
- What is the total grief level of guardian caregivers?
- What specific stressors has HSCT placed on the guardian caregivers? Family?
- How has HSCT affected personal relationships within the family?

Population, Sample and Setting

A convenience sample of eight to ten guardian sets is recommended from a Midwestern hospital. The guardian sets must be twenty years of age or older, male or female, and single, married, divorced, or widowed.

Protection of Human Subjects

This study should be submitted to both university Institutional Review Board (if applicable) and to the facility's Institutional Review Board where the study will be conducted. The participants would be included on a voluntary basis only. A cover letter addressing the purpose of the study, the purpose of the questionnaire, and a statement explaining that their identities will remain anonymous at all times would be included and explained. Informed consent would be obtained. The informed consents, demographic information, questionnaire responses, and voice recordings will be treated as confidential

and kept in a locked container with access limited to the investigator. Identified risks would be minimal, but may involve an emotional response from the participant from speaking about his/her child's condition and/or how it has affected him/her and/or his/her family.

Procedure

Upon receiving permission from the appropriate Institutional Review Boards, the researcher will post a flier in a well-trafficked area on the unit with an explanation of the purpose of the study and the researcher's contact information if interested. Once the researcher is contacted through a secure connection, the researcher should interview the potential participant to ensure that he/she qualifies to participate in the study and to verify interest. When qualification and interest has been verified, the researcher should schedule a time to conduct the study. Immediately before the study commences, the researcher should provide the cover letter addressing the purpose of the study, the purpose of the questionnaire, and statement explaining that their identities will remain anonymous at all times and explain and obtain an informed consent.

The researcher should then begin the study by having the guardian(s) complete a form addressing demographic information (Form 1). Upon completion of this form, the researcher should begin the qualitative portion of the study by recording the interview questions and answers addressed in Table 1, ensuring enough time for the participant(s) to fully share their answers. Once the qualitative portion of the study is complete, the researcher should have the guardian(s) complete the Modified MM-CGI. When this questionnaire is complete, the researcher should thank the participant(s) and offer information about additional resources if requested. This process should be repeated

until the qualitative information is saturated with repetition of themes in participant responses.

Instrumentation, Reliability and Validity

The researcher should begin by encouraging the participants to provide the demographic and background information in Form 1. This form identifies the patient's diagnosis and treatment history, the caregiver's relationship to the patient, general income information, and additional children information. Table 1 provides the qualitative questions that the investigator should explore with the participants. To ensure reliability and validity, the investigator must develop a coding system upon replaying the interviews and proceed with further interviews until all of the information has been saturation and themes have been repeated. The final instrument is the MM-CGI Childhood Cancer and will provide complimentary quantitative data. Al-Gamal et al. (2009) developed a modified version of the MM-CGI to measure anticipatory grieving in Jordanian parents of pediatric oncology patients called the MM-CGI Childhood Cancer and shows great promise in measuring the burden of grief (subjective burden) in caregivers of pediatric oncology patients treated with HSCT. The fifty-item tool with some reverse coding and a five-point Likert-type response format (1 = "strongly disagree" to 5 = "strongly agree") measures personal sacrifice burden, heartfelt sadness and longing, and worry and felt isolation. In 2006, the tool was administered to 140 Jordanian parents living with a child with cancer. The Cronbach α coefficient for the total instrument was 195, and the Cronbach α coefficients for each of the three subscales was .91 for personal sacrifice burden, .90 for heartfelt sadness and longing, and .86 for worry and felt isolation (Al-Gamal et al., 2009). The validity of the instrument was

supported by the demonstration of a positive correlation to the Anticipatory Grief Scale (Levy, 1991). Due to the use of the instrument with a qualitative piece, the MM-CGI Childhood Cancer should be examined for further internal consistency using the Cronbach α coefficient with a smaller sample size.

Research Design

This is an exploratory descriptive study because three different measurement pieces will be used to collect data: the demographic and background information form, the qualitative research interview questions, and the quantitative MM-CGI Childhood Cancer. Triangulation will be used to cross-examine the results of the data.

Data Analysis

For the qualitative portion of the study, the investigator must develop a coding system to identify common themes shared in the participant interviews. Descriptive statistics will be used to measure the results of the MM-CGI Childhood Cancer with the Cronbach α coefficient measuring for internal consistency. Once all of the demographic data (Form 1), qualitative data (Table 1), and quantitative data (MM-CGI Childhood Cancer) have been collected, the chi-square statistical test will be used to determine whether there is a significant relationship among the data (Cozby, 2009).

Summary

Caregiver role strain and burden is a significant risk in guardian caregivers of pediatric oncology patients treated with HSCT. The severity of the illness and the care required for the pediatric oncology patient who has received HSCT can be overwhelming for caregivers and deserves examination on the part of the health care provider. Through exploring the relationship among demographic data, qualitative data, and quantitative data, the investigator is able to identify specific stressors and areas of burden for caregivers. A plan specific to the guardian caregivers can then be created to alleviate these stressors and provide needed resources.

References

Al-Gamal, E., Long, T., & Livesley, J. (2009). Development of a modified instrument to measure anticipatory grieving in Jordanian parents of children diagnosed with cancer: The Marwit and Meuser Caregiver Inventory childhood cancer. *Cancer Nursing* 2009; 32(3):211-219.

American Cancer Society. (2009). Cancer Statistics 2009 Presentation [PowerPoint Slides]. Retrieved from http://www.cancer.org/docroot/PRO/content/PRO_1_1_Cancer_Statistics_2009_Presentation.asp

Berman, A., Snyder, S.J., Kozier, B., & Erb, G. (2008) *Kozier & Erb's fundamentals of nursing concepts, process, and practice* (8th ed.). Upper Saddle River, New Jersey: Pearson Education, Inc.

Blanchard, C.G., Albrecht, T.L., & Ruckdeschel, J.C. (1997). The crisis of cancer: Psychological impact on family caregivers. *Oncology* 1997; 11(2): 189-194.

Centers for Disease Control and Prevention (CDC). (2007). Trends in childhood cancer mortality—United States, 1990–2004. *MMWR* 2007; 56(48):1257–1261.

Cozby, P.C. (2009). *Methods in behavioral research* (10th ed.). New York: McGraw Hill.

Fadden, G., Bebbington, P., & Kuipers, L. (1987). The burden of care: The impact of functional psychiatric illness on the patient's family. *The British Journal of Psychiatry* 1987; 150: 285-292.

Gaugler, J. E., Linder, J., Given, C.W., Kataria, R., Tucker, G., & Regine, W.F. (2008) The proliferation of primary cancer caregiving stress to secondary stress. *Cancer nursing* 2008; 31(2): 116-123.

Given, C.W., Given, B., Stommel, M., Collins, C., King, S., & Franklin, S. (2007). The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Research in Nursing & Health* 2007; 15(4): 271-283.

Herdman, T.H. (Ed.). (2009). *NANDA International nursing diagnoses: Definitions and classification 2009-2011.* Ames, Iowa: John Wiley & Sons Ltd.

Hockenberry, M.J., & Wilson, D. (2009). *Wong's essentials of pediatric nursing* (8th ed.). St. Louis, Missouri: Elsevier.

Honea, N.J., Brintnall, R., Given, B., Sherwood, P., Colao, D.B., Somers, S.C., & Northouse, L.L. (2008). Putting evidence into practice®: Nursing assessment and interventions to reduce family caregiver strain and burden. *Clinical Journal of Oncology Nursing* 2008; 12(3): 507-513.

Jemal, A., Siegel, R., Ward, E., Hao, Y., Xu, J., & Thun, M.J. (2009). Cancer statistics, 2009. *CA: A Cancer Journal for Clinicians* 2009; 59(4):225–249.

Lazarus, R.S., & Folkman, S. (1984). *Stress, appraisal, and coping.* New York: Springer Publishing Company.

Levy, L. (1991). Anticipatory grief: Its measurement and proposed reconceptualization. *Hosp J.* 1991; 7(4): 1-28.

Lewis, S.L., Heitkemper, M.M., Dirksen, S.R., O'Brien, P.G., & Bucher, L. (2007). *Medical-surgical nursing: Assessment and management of clinical problems* (7th ed.). St. Louis, Missouri: Elsevier.

Marwit, S.J., & Meuser, T.M. (2002). Development and initial validation of an inventory to assess grief in caregivers of persons with Alzheimer's disease. *The*

Gerontologist 2002; 42(6): 751-765.

Meuser, T.M., & Marwit, S.J. (2001). A comprehensive, stage-sensitive model of grief in dementia caregiving. *The Gerontologist* 2001; 41(5): 658-770.

National Marrow Donor Program. (2010). Be The Match Registry. Retrieved from http://www.marrow.org

Ow, R. (2003). Burden of care and childhood cancer: Experiences of parents in an Asian context. *Health & Social Work* 2003; 28(3): 232-240.

Perlin, L.I., Mullan, J.T., Semple, S.J., & Skaff, M.M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist* 1990; 30: 583-594.

Sanders, S., Ott, C.H., Kelber, S.T., & Noonan, P. (2008). The experience of high levels of grief in caregivers of persons with Alzheimer's disease and related dementia. *Death Studies* 2008; 32: 495-523.

Schmidt-Pokorny, K. (2009). Expanding indications for stem cell transplantation. *Seminars in Oncology Nursing* 2009; 25(2): 105-114.

U.S. Cancer Statistics Working Group. (2010). *United States cancer statistics: 1999–2006 incidence and mortality web-based report*. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2010. Retrieved from http://apps.nccd.cdc.gov/uscs/childhoodcancerbyprimarysite.aspx

Form 1: Demographic and Background Information

Participant #:_____

Child's information

Child's Age:_____Child's Current Grade in School _____ Child's sex: M_____ F _____

Race/ethnicity: _____

What is your child's diagnosis?_____

Has your child received hematopoietic stem cell transplantation? Y_____ N _____

If yes, when? _____

If no, when will he/she receive it? _____

Please indicate whether your child has received the following treatments:

Procedure/Treatment		
Surgery?	Y ____ N____	If yes, what procedure? _____
Chemotherapy?	Y ____ N____	If yes, how many rounds? _____
Radiation?	Y ____ N____	If yes, how many rounds? _____
		To what area(s)? _____
Other?	Y ____ N ____	Explain_____

Guardians' information

Number of Guardian Caregivers in Interview:

_____

Relationship status to each other (if applicable): _____

Relationship status to child (receiver of care): _____

Estimated annual income (check one):

____ 1. < $15,000
____ 2. $15,000-24,999
____ 3. $25,000-34,999
____ 4. $35,000-44,999
____ 5. $45,000-54,999
____ 6. $55,000-64,999
____ 6. $65,000-99,999
____ 6. >$100,000

Guardian Caregiver 1 Information
Age: _____ Employment Status: _____

Guardian Caregiver 2 Information
Age: _____Employment Status: _____

Highest level of education completed (check one):

Guardian Caregiver 1	Guardian Caregiver 2
____ ½ Some high school	____ 1. Some high school
____ 2. Completed high school	____ 2. Completed high school
____ 3. Some college	____ 3. Some college
____ 4. 2-year degree	____ 4. 2-year degree
____ 5. 4-year degree	____ 5. 4-year degree
____ 6. Graduate degree	____ 6. Graduate degree

Are there other children in the household? Y____ N ____ If yes, what are their ages? _____

Table 1: Qualitative Questions

1. Tell me about your initial feelings when you first learned of your child's diagnosis.
2. How many hours a day would you say that you spend thinking about your child's diagnosis?
3. What is it like watching your child go through treatment?
4. How has your child's diagnosis and treatment affected your family dynamic? Your romantic relationship/marriage? Relationship with your other children? Relationship between your child and his/her siblings?
5. How has your child's diagnosis and treatment affected your relationship you're your other support systems (i.e. extended family, friendships)?
6. How has your child's diagnosis and treatment affected your work/career? Leisure activities?
7. How has your child's diagnosis and treatment affected your personal health?
8. How has your child's diagnosis and treatment affected your caregiving responsibilities as a parent?
9. How does the process involved in stem cell transplantation compare with other treatments that your child has received?
10. Tell me about feelings that you currently have about transplantation and any additional ways it has affected your life.

MM Caregiver Grief Inventory Childhood Cancer

Original MM-CGI Created by:
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Instructions: This inventory is designed to measure the grief experience of current family caregivers of persons living with progressive dementia (e.g., Alzheimer's disease), but it has been modified to address the grief of caregivers of pediatric oncology patients. Read each statement carefully, and then decide how much you agree or disagree with what is stated.

Circle a number 1-5 to the right using the answer key below (For example 5 = Strongly Agree). It is important that you respond to all items so that the scores are accurate. Scoring rules are listed at the end.

ANSWER KEY

1 = Strongly Disagree; 2 = Disagree; 3 = Somewhat Agree; 4 = Agree; **5 = Strongly Agree**

1	I've had to give up a great deal to care for my child since diagnosis.	1 2 3 4 5	A
2	I miss so many of the activities I used to share with my child since the diagnosis was made.	1 2 3 4 5	B
3	I feel I am losing my freedom.	1 2 3 4 5	A
4	My physical health has declined from the stress of being a caregiver.	1 2 3 4 5	A
5	I have nobody to communicate with.	1 2 3 4 5	C
6	I don't know what is happening. I feel confused and unsure.	1 2 3 4 5	C
7	I carry a lot of stress caring for my child since the diagnosis was made.	1 2 3 4 5	A
8	I receive enough emotional support from others.	1 2 3 4 5	Cr
9	I have this empty, sick feeling knowing that my child was diagnosed with this illness.	1 2 3 4 5	B
10	I feel anxious and scared.	1 2 3 4 5	C
11	My personal life has changed a great deal.	1 2 3 4 5	A
12	I spend a lot of time worrying about the bad things to come.	1 2 3 4 5	C
13	This diagnosis is like a double loss…I've lost the closeness with my child and connectedness with my family.	1 2 3 4 5	C

14	I feel terrific sadness.	1 2 3 4 5	B
15	The diagnosis of my child with this illness is totally unacceptable in my heart.	1 2 3 4 5	B
16	My friends simply don't understand what I'm going through.	1 2 3 4 5	C
17	I feel this constant sense of responsibility and it just never leaves.	1 2 3 4 5	A
18	I long for what was, what we had and shared in the past.	1 2 3 4 5	B
19	I could deal with other serious treatments better than with this.	1 2 3 4 5	B
20	I can't feel free in this situation.	1 2 3 4 5	A
21	Since the diagnosis I'm having trouble sleeping.	1 2 3 4 5	A
22	I'm at peace with myself and my situation in life.	1 2 3 4 5	Cr
23	I know we'll get through it.	1 2 3 4 5	Cr
24	My extended family has no idea what I go through in caring for him/her.	1 2 3 4 5	C
25	I feel so frustrated that I often tune my child's diagnosis out.	1 2 3 4 5	A
26	I am always worrying.	1 2 3 4 5	C
27	I'm angry at the disease for rubbing me of so much.	1 2 3 4 5	B
28	This is requiring more emotional energy and determination than I ever expected.	1 2 3 4 5	A
29	I will be tied up with this for who knows how long.	1 2 3 4 5	A
30	It hurts to put my child in bed at night knowing that that she/he is diagnosed with this illness.	1 2 3 4 5	B
31	I feel very sad about what this disease has done.	1 2 3 4 5	B
32	I feel severe depression.	1 2 3 4 5	C
33	I lay awake most nights worrying about what's happening and how I'll manage tomorrow.	1 2 3 4 5	C
34	The people closest to me do not understand what I'm going through.	1 2 3 4 5	C
35	My child's recovery will bring me renewed personal freedom to live my life.	1 2 3 4 5	A
36	I feel powerless since my child's diagnosis.	1 2 3 4 5	B
37	It's frightening because you don't know if doctors can cure this disease, so things may only get worse.	1 2 3 4 5	B
38	The losses I'm experiencing since my child's diagnosis are much more troubling than any I've experienced before.	1 2 3 4 5	B
39	Independence is what I've lost…since my child's diagnosis I don't have the freedom to go and do what I want.	1 2 3 4 5	A
40	I've had to make some drastic changes in my life as a result of becoming a caregiver.	1 2 3 4 5	A
41	I wish I had an hour or two to myself each day to pursue	1 2 3 4 5	A

	personal interests.		
42	I'm stuck in this caregiving world and there's nothing I can do about it.	1 2 3 4 5	A
43	I can't contain my sadness about all that's happening.	1 2 3 4 5	B
44	What upsets me most is what I've had to give up.	1 2 3 4 5	A
45	I'm managing pretty well overall.	1 2 3 4 5	Cr
46	I think I'm denying the full implications of this for my life.	1 2 3 4 5	C
47	I get excellent support from members of my family.	1 2 3 4 5	Cr
48	I've had a hard time accepting what is happening.	1 2 3 4 5	B
49	The demands on me are growing faster than I ever expected.	1 2 3 4 5	A
50	I wish this was all a dream and I could wake up back in my old life.	1 2 3 4 5	B

Self-Scoring Procedure: Add the numbers you circled to derive the following sub-scale and total grief scores. Use the letters to the right of each score to guide you. *C Items with "r" afterwards must first be reverse scored (1* changed to *5, 2* changed to *4, 3* changed to *3, 4* changed to *2, 5* changed to *1) before adding to calculate your scores.*

Personal Sacrifice Burden *(A Items)* = _____
(18 Items, M = 54.3, SD = 14.1, Alpha = .93, Split-Half = .91)

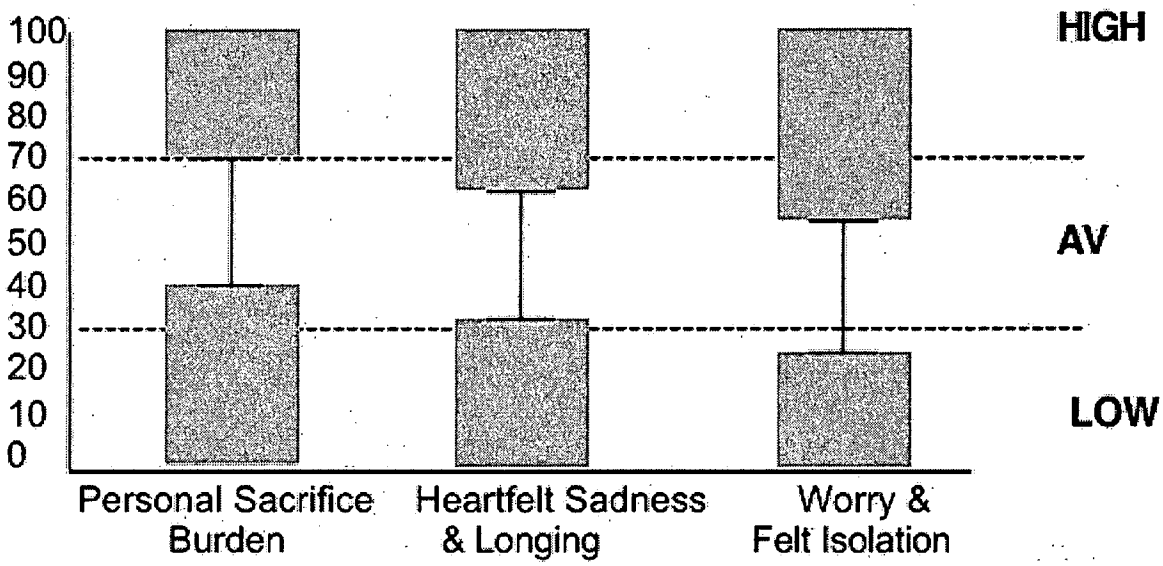
Heartfelt Sadness & Longing *(B Items)* = _____
(15 Items, M = 48.2, SD = 11.1, Alpha = .90, Split-Half = .86)

Worry & Felt Isolation *(C Items)* = _____
(17 Items, M = 40.6, SD = 11.9, Alpha = .91, Split-Half = .91)

Total Grief Level (Sum A + B + C) = _____
(50 Items, M = 144, SD = 31.6, Alpha = .96, Split-Half = .87)

Plot your scores using the grid on the following page. Make an "**X**" in the shaded section nearest to your numeric score for each sub-scale. This is your grief profile. Discuss this profile with your nurse.

MM-CGI Personal Grief Profile



What do these scores mean?

Scores in the top area are higher than average based validation sample statistics (1 SD above the Mean). High scores may indicate a need for formal intervention or support assistance to enhance coping. Low scores in the bottom lined section (1 SD below the Mean) may indicate denial or a downplaying of distress. Low scores may also indicate positive adaptation if the individual is not showing other signs of suppressed grief. Average scores in the center indicate common reactions. These are general guides for discussion and support only – more research is needed on more specific interpretation issues.